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Abstract

Parents of children with Down syndrome face many challenges related to their children's disability. They manage to raise their children primarily thanks to their internal resources, protective psychological traits and help from other people. The aim of this study was to investigate the level of ego-resiliency as an important personality trait in a group of mothers and fathers of children with Down syndrome. The relationship between ego-resiliency and parental satisfaction was also studied.

The sample consisted of 126 parents (75 mothers and 51 fathers). Our results show that there is no difference in the level of ego-resiliency between mothers and fathers of children with Down syndrome. Nevertheless, it is noticed that there is a difference in perceived stress, psychological well-being and some aspects of parental satisfaction between parents with high and low levels of ego-resiliency. These results give an interesting insight into the internal functioning of parents of children with Down syndrome.

Keywords: *children, parents, Down syndrome, ego-resiliency, parental satisfaction*

Introduction

It is commonly known that a child's illness or disability restricts its parents comfortableness and activity possibilities and forces them to focus entirely on problems of everyday life. When a child with Down syndrome is born, its parents

have to face many new duties and obstacles in their life. Although the personality structures of parents of healthy children and parents of children with Down syndrome do not differ and allow them to use similar strategies to cope with stress, mothers and fathers of children with Down syndrome feel more depressed (Sadowska, Gruna-Ożarowska, Mysłek-Prucnal, 2007). Parents of children with Down syndrome perceive child- and parent-related stress as stronger than do parents of healthy children (Roach, Orsmond, Barratt, 1999). However, a lot of mothers and fathers of children with Down syndrome do not tend to describe their parenthood only in negative terms such as burden or stress (Przybyła-Basista, Kózka, 2016) and are able to notice positive changes caused by the situation of looking after a child with disability (Joosa, Berthelsen, 2006; King, Zwaigenbaum, Bates, Baxter, Rosenbaum, 2011; Przybyła-Basista, Kózka, 2016). Also, mothers of adult children with Down syndrome tend to perceive their relationship with their children as more satisfying than mothers of children with schizophrenia or children with autism (Greenberg, Seltzer, Krauss, Chou, Hong, 2004). By the virtue of above facts it can be inferred that in spite of a child's disability the family is capable of endurance and resilience.

In the context of being a parent of a child with disability, resilience can be considered from various perspectives. One of them is emotional resilience which protects from apathy, depressive or anxiety states and an extreme form of egocentrism (Wolska, 2013). It should be remembered that resilience is not a trait which determines one's success or failure as a final result of a difficult situation, but it is understood as a psychical process which regulates one's resistance resources and gives an ability to bounce back from negative life events despite unfavourable circumstances (Masten, Powell, 2003). On the basis of the results which show that parents who cope with their child's Down syndrome are able to become more aware of life priorities, change their plans and make the family patterns more adaptable (King et al., 2005), it can be supposed that in this group of parents factors related to resilience are present. One of these factors is ego-resiliency, which determines adaptation to traumatic as well as everyday life events (Sęk, 2008). The construct of ego-resiliency is defined as one's ability to regulate impulses and change the level of self-control in the presence of various stressors (Block, Kremen, 1996). Resiliency is a personality trait. Individuals with psychological resiliency are capable of overcoming difficulties in life and getting stronger as a result of these difficulties (Ogelman, Erol, 2015). Both resilience and ego-resiliency play an important role in the process of coping with a high level of stress – they allow for "going away" from negative experiences and arousing emotions which are considered as positive (Heszen, Sęk, 2007). The presence of ego-resiliency can also

stimulate openness to new experiences (Block, Kremen, 1996). In this sense, these resources seem to be very important for parents who have to redefine their aims and dreams in the face of their children's disability.

Differences in ego-resiliency are present at the moment of birth and during adulthood it is helpful to adapt successfully to various situations and cope well with difficulties (Ong, Bergeman, Bisconti, Wallach, 2006). People with a high level of ego-resiliency demonstrate better adaptation between personality traits and environment, their behaviour is more often interpreted as positive and it is more stable (Asendorpf, van Aken, 1991). A person whose ego-resiliency has a relatively high level, also shows life energy, enthusiasm, curiosity and self-confidence. Moreover, such people are able to regain balance after stressful situations with ease, they do not feel resentment for a long time, like themselves and their life, and have a positive attitude to other people (Block, Kremen, 1996). Successful development of ego-resiliency helps to choose solutions which have the strongest influence on adjustment in concrete situations (Kaczmarek, Sęk i Ziarko, 2011). On the other end of predispositions which are helpful in coping with difficulties, researchers situate "ego-brittleness": this construct can be defined as lack of adequate self-control, which can lead to negative feelings such as fear (Block, Kremen, 1996). People with lower levels of ego-resiliency tend to focus on failures, have little emotional diversity and often suffer from a lack of meaning of life (Kaczmarek, Sęk, Ziarko, 2011).

For the above reasons, and taking into account our previous results (Kózka, Przybyła-Basista, 2016), which show that stress perceived by parents has a weaker effect on their psychological well-being when they have at their disposal such resources like ego-resiliency, we assume that ego-resiliency can play an important role in perceiving stress and gaining psychological well-being as well as parental satisfaction in parents of children with Down syndrome.

We put forward a hypothesis that there is a difference in psychological functioning between parents with different levels of ego-resiliency. The following research questions are posed:

1. Is there any difference in ego-resiliency and its components (optimal regulation and openness to experiences) between mothers and fathers of children with Down syndrome?
- 2a. Is there any difference in perceived stress between parents of children with Down syndrome, who have low and high levels of ego-resiliency?
- 2b. Is there any difference in psychological well-being between parents of children with Down syndrome, who have low and high levels of ego-resiliency?
- 3a. Is there any difference in satisfaction with parental role between parents of children with Down syndrome, who have low and high levels of ego-resiliency?

- 3b. Is there any difference in satisfaction with relations with the child between parents of children with Down syndrome, who have low and high levels of ego-resiliency?

Research Methodology

Participants and procedure

The participants in this study were 126 parents of children with Down syndrome, of whom 59.52% ($n = 75$) were mothers and 40.48% ($n = 51$) – fathers. The parents' age ranged from 25 to 69 years with the mean age = 46.54 ($SD = 10.26$). All the parents were married at the time of participation in this study. The age of children (with Down syndrome) of the parents ranged from 1 to 39 ($M = 13.25$, $SD = 8.90$). The majority of the parents (42.98%) had higher education and described their financial situation as satisfactory (46.72%), or good and very good (44.26%). The parents were citizens of Polish big cities (47.83%), smaller towns (33.91%) and villages (18.26%).

Each parent was asked to agree to participate in the study and was ensured that participation would be anonymous. The survey was conducted through individual contacts as well as with the help of institutions and volunteers.

Instruments

Ego-resiliency. The level of ego-resiliency was measured with the Ego-Resiliency scale developed by Block and Kremen (1996). Its Polish adaptation was conducted by Przybyła-Basista and Kołodziej (2012). This scale consists of 12 items, e.g., "I am generous with my friends". Each item has a 4-point response scale (4 = "I agree very strongly" and 1 = "I do not agree at all"). The Polish version of the scale structure consists of two factors: Optimal Regulation (OR) and Openness to Experience (OL). Cronbach's α for the total scale was 0.802, for the OR scale = 0.773 and for the OL scale = 0.59.

Perceived stress. The level of parents' perceived stress was evaluated with the use of the 10-item Perceived Stress Scale (PSS-10) developed by Cohen, Kamarck and Mermelstein (1983), in Polish adaptation by Juczyński and Ogińska-Bulik (2009). The instrument focuses on negative stress experienced during the month prior to the survey. The respondents rated their level of agreement for each item on a 5-grade scale, where 0 denotes "never" and 4 – "very often." The PSS-10 scores are obtained by reversing the scores on the four positive questions and then summing up across all 10 scores. Example questions include "In the last month, how often

have you found that you could not cope with all the things that you had to do?” Cronbach's α coefficient for this scale is 0.86.

Psychological well-being. The Oxford Happiness Questionnaire (OHQ; Hills and Argyle, 2002), in Polish adaptation by Kołodziej and Przybyła-Basista (2013), was used to measure the parents' psychological well-being. The respondents rated their level of agreement for each item on a 6-grade scale where 6 = "I absolutely agree" and 1 = "I absolutely disagree". Cronbach's α for the total scale was 0.902.

Parental satisfaction. To investigate the parents' personal satisfaction with themselves as a parent and the relationship with their child (a child with Down syndrome), we proposed two separate questions ("Are you satisfied with yourself as a parent?" and "Are you satisfied with your relationship with your child? [a child with Down syndrome]"). The questions were rated on a 3-grade scale with responses ranging from 1 to 3, where 1 denotes "I am dissatisfied", 2 – "I am rather satisfied" and 3 – "I am satisfied".

Research Results

The first objective of this study was to probe into the question whether there is any difference in the level of ego-resiliency and its components between mothers and fathers of children with Down syndrome. The results obtained with the use of *U* Mann-Whitney test showed that there is no significant difference in ego-resiliency and its components between those two groups of parents ($p > .05$). Results of the analysis are shown in Tables 1a and 1b.

Table 1a. Ego-resiliency in the group of mothers and in the group of fathers of children with Down syndrome

Ego-resiliency	n	M	Mdn	Min.	Max.	SD
Mothers	75	33.23	32.00	17.00	48.00	6.24
Fathers	51	33.98	34.00	22.00	46.00	6.32

Table 1b. Ego-resiliency in the group of mothers and in the group of fathers of children with Down syndrome (comparison with the use of *U* Mann-Whitney test)

Variable	Mean rank Mothers	Mean rank Fathers	<i>U</i>	<i>Z</i>	<i>P</i>
<i>Ego-resiliency</i>	61.76	66.06	1782.00	-0.65	0.52
<i>Ego-resiliency Optimal Regulation</i>	63.45	63.57	1909.00	-0.01	0.99
<i>Ego-resiliency Openness to Experience</i>	60.25	68.27	1669.0	-1.21	0.23

The second purpose was to get an insight into whether there is any difference in the level of perceived stress, psychological well-being and chosen aspects of parental satisfaction between parents with different levels of ego-resiliency. The group of parents was divided into two subgroups with the use of median ($Mdn = 33.00$): the parents who obtained scores greater than the value of the median ($Mdn > 33.00$) were classified as a high ego-resiliency group; the parents with scores equal to the value of the median or less ($Mdn \leq 33.00$) were called a low ego-resiliency group.

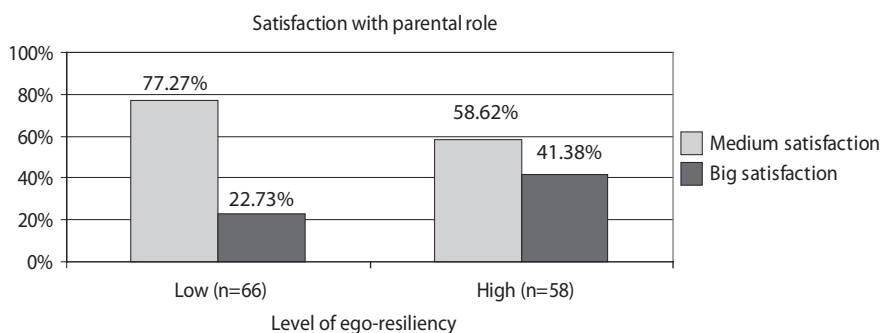
The results obtained with the use of Student's t -test showed that there is a significant difference in perceived stress and psychological well-being between the parents who have low and those who have high levels of ego-resiliency ($p = .001$). The parents who have a low level of ego-resiliency perceive their stress as bigger ($M = 21.00$, $SD = 6.29$) than the parents with a higher level of ego-resiliency ($M = 16.40$, $SD = 6.21$). What is more, the parents who had higher levels of ego-resiliency obtained better scores in psychological well-being ($M = 105.65$, $SD = 15.42$) than the parents whose ego-resiliency level was lower ($M = 92.38$, $SD = 17.64$). Results of the analysis are shown in Table 2.

Table 2. Perceived stress and psychological well-being among parents of children with Down syndrome with a low or high level of ego-resiliency

Variable	Ego-resiliency	<i>M</i>	<i>SD</i>	<i>SE</i>	<i>t</i>	<i>df</i>	<i>p</i>
Perceived stress	low ($n = 65$)	21.00	6.29	0.78	-4.131	124	.001
	high ($n = 61$)	16.40	6.21	0.79			
Psychological well-being	low ($n = 65$)	92.38	17.64	2.26	4.503	124	.001
	high ($n = 61$)	105.65	15.42	1.91			

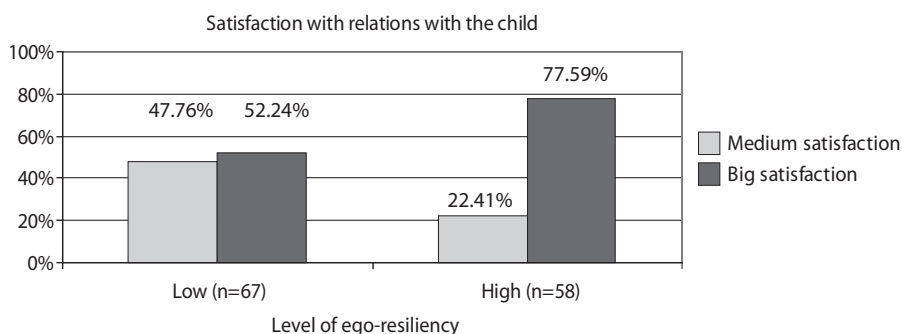
To examine whether there is any difference in the level of selected aspects of parental satisfaction between the parents with different levels of ego-resiliency, we used the Chi-squared test. Our results show that there is a significant difference in satisfaction with parental role and satisfaction with relations with the child (a child with Down syndrome) between the parents who have a low level of ego-resiliency as compared to those who have a high level of ego-resiliency ($p = .001$). The parents whose ego-resiliency level is higher tend to declare bigger satisfaction with their parental role ($p = .026$) and relations with the child ($p = .003$) than the parents who have a low level of ego-resiliency (cf., Figures 1a and 1b).

Figure 1a. Satisfaction with parental role among the parents of children with Down syndrome with low or high levels of ego-resiliency



STATISTICS of the model: $\chi^2 = 5.86$, $df = 1$, $p = 0.026$

Figure 1b. Satisfaction with relations with the child among the parents of children with Down syndrome with low or high levels of ego-resiliency



STATISTICS of the model: $\chi^2 = 8.67$, $df = 1$, $p = 0.003$

Discussion and conclusions

Our previous research results show that ego-resiliency plays an important mediating role in the relationship between the perceived stress and psychological well-being of parents of children with Down syndrome (Kózka, Przybyła-Basista, 2016). In particular, we suggested that especially in the group of fathers, ego-resiliency is essential in maintaining psychological well-being (Kózka, Przybyła-Basista, 2017). Therefore, the aim of the present study was to check whether mothers and fathers of a child with Down syndrome differ with regard to the ego-resiliency levels.

According to the results obtained in this study, the mothers and fathers of children with Down syndrome do not differ in the level of ego-resiliency. It can be interpreted that, although mothers and fathers may have similar possibilities of coping using this inner resource, the mechanisms maintaining their psychological well-being are different. Ego-resiliency is an essential predictor of psychological well-being for fathers, while for mothers it is perceived social support (Kózka, Przybyła-Basista, 2017).

Our results also show that the parents with high ego-resiliency report lower levels of perceived stress and higher levels of psychological well-being in comparison with the parents with low ego-resiliency. Quite importantly, within the group of parents with high ego-resiliency parental satisfaction was significantly higher than that in the low ego-resiliency group. Also, in the high ego-resiliency group there were more parents who reported satisfaction with the relations with their own children.

Therefore, the parents who have higher levels of ego-resiliency evaluate themselves better as parents as well as their relations with the child. It can be inferred that the parents who have a high level of ego-resiliency will adapt themselves more easily to the role of a parent of a child with Down syndrome. These conclusions can be helpful in identifying potential factors facilitating parents adaptation to the parental role of a child with mental disability. These findings are compatible with psychological theories suggesting that ego-resiliency is an important factor which can alleviate stress and give endurance. By the virtue of the fact that subjective psychical properties have an influence on a coping strategy and situation assessment (Juczyński, Ogińska-Bulik, 2009), ego-resiliency can be considered as a factor which has an impact on individual and relational functioning of parents. Resilience can positively strengthen the mental functions of the family members and enhance their personal ability to cope with emotional and psychological difficulties related to the mental disability of their child (Badiie, 2016).

It should be pointed out that the present study has an exploratory character. One limitation resulted from the fact of using only two simple questions to investigate personal satisfaction with oneself as a parent and the relationship with the child. In further research, parental satisfaction should be measured with a questionnaire that has good psychometric parameters. Therefore, it would be necessary to adapt foreign questionnaires to Polish conditions or to develop a new measuring tool that takes into account the specific context of a mentally disabled child.

Despite the above limitations, this study is a contribution to a discussion about the role of inner resources, especially ego-resiliency, in the process of adaptation to the role of a parent of a child with Down syndrome. The birth of a child with

disability usually gives parents a sense of being trapped, with no possibility of escape (Będkowska-Heine, 2007). In this context, it is very important to recognise parents' potential of coping with their situation and using appropriate forms of help. Ego-resiliency may be helpful in optimising the way in which parents of mentally disabled children function in their parental roles. Further research in this area should focus, among other topics, on in-depth analysis of traits which play a protective role for mothers and fathers of children with Down syndrome in the adaptation process of their parental functioning.

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